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## CIRM Innovation: The Patient Advocate Role -- Guest blogger Jeff Sheehy

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Duane Roth, my colleague on the CIRM governing board where he serves as one of the vice-chairs, has just published an article, with the title, "The Third Seat at the Table: An Insider's Perspective on Patient Representatives," in the Hasting's Center Report. The Center, an independent, nonpartisan, and nonprofit bioethics research institute, publishes its report six times a year to "explore the ethical, legal, and social issues in medicine, health care, public health, and the life sciences."

His article, along with one I published in Nature earlier this year ("Advocates deserve room at the decision-making table") describe one of the critical innovations found in the governance of CIRM: formal, powerful roles for patient advocates.

I serve on the governing board as a patient advocate for HIV/AIDS, and in that role I along with the other patient advocate board members have been able to directly influence the direction of the agency. Our voice has helped shape decisions regarding CIRM policies and funding. As Roth writes, patient advocates can grasp some of the most complex and thorny policy and scientific issues and "tip the scales" in the direction of sound public policy that seeks prudently to accelerate progress towards cures.

In his essay, Roth describes the genesis of active and vocal patient power through the response to AIDS in the 1980s and 90s, "which galvanized patient communities to unprecedented levels of scientific and political involvement." He also points out the current struggles between advocates and the FDA, where patients with multiple sclerosis and prostate cancer have been frustrated by the agency's decisions.

Roth forcefully argues for incorporating a formal role for "patient mediators" into the FDA's product approval processes. "The costs would be negligible, and the payoffs in therapeutic efficiency, and procedural efficiency, and public confidence could be enormous."

In my Nature article, I link the successful passage of Proposition 71 establishing CIRM to the unprecedented efforts of patient advocates around California and argue that scientists and policymakers have an obligation to include in the decision-making processes those who make their work possible.

As pluripotent (embryonic or iPS) cell approaches enter clinical space, formal inclusion of patient advocates into decision making roles along the lines suggested by Roth is absolutely essential if society is going to judiciously accept the inevitable failures that accompany most clinical research. Cell therapy has the potential to transform medicine, but the risks are as great as the potential.

In HIV/AIDS, we have seen risk mitigated by the unwavering willingness of an active patient and stakeholder community to tolerate failure. The patient communities seeking relief and cures through cell therapy are just as capable of evaluating and accepting risks and failures.

I would argue that Roth's article with its recommendations is not only timely, but also urgent, and I hope that it inspires a dialogue leading to near term conclusive action to bring patient advocates into the decision-making process regarding new therapies.

- Jeff Sheehy is is director for communications at the AIDS Research Institute at UCSF, and a member of the CIRM governing board.

Tags: sheehy, HIV/AIDS, patient advocates